Epilepsy in a Doncaster practice: audit and change over eight years

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SUMMARY. The results of active management and the findings of repeated audits of epilepsy care over the period 1978–86 in a general practice are described. It was found that about one-fifth of epileptic patients continued to have frequent seizures, usually complex partial, about half had few seizures, and many with mild epilepsy remitted early.

By 1980 attempts to reduce polypharmacy, change treatment and achieve optimal use of anticonvulsant drugs in epileptic patients with frequent seizures or side effects had led to an overall improvement in seizure control in 27%, a reduction of polypharmacy in 24% and an improvement in well-being in many patients. Subsequently it proved possible to maintain this improvement, to achieve similar results in epileptic patients joining the practice and to avoid misdiagnosis and polypharmacy in newly diagnosed patients.

General practitioners can make a considerable contribution to the care of patients with epilepsy but improved overall care requires better collaboration between neurologists and other clinicians. A district epilepsy service, based on a local clinic, which actively pursues a collaborative approach is suggested as the model for providing optimum care to epilepsy patients.

Introduction

MOST audits or surveys of epilepsy[1-5] have, with one exception,[6] demonstrated inadequacies in care. In addition, there have been few reports of actual change occurring as a result of altered practice policies,[7,8] and none of long-term effects on patient care. Few changes have resulted from recommendations made in successive reviews and reports since the late 1960s[9] and an important earlier recommendation, restated recently,[10] calls for special epilepsy clinics.

Epilepsy care in Doncaster is shared between neurologists, paediatricians, general physicians and general practitioners and is probably typical of epilepsy care in the UK. A visiting neurologist from a teaching hospital 25 miles away conducts one outpatient clinic in the local district general hospital each week. Although new patients receive an excellent initial clinical evaluation, long waiting times for outpatient appointments occur and opportunities for detailed counselling and follow up are limited. Local paediatricians are able to provide evaluation and continuing support for children with epilepsy but the management of most chronic epilepsy becomes the responsibility of general practitioners.

In recent years improved seizure control and reduced side-effects have been demonstrated as a result of effective monotherapy and reduction in the number of drugs in both new and chronic patients attending hospital.[11,12] Awareness of poor seizure control and problems with polypharmacy in patients with chronic epilepsy in a Doncaster urban practice led one partner with a special interest in epilepsy to review all patients thought to have epilepsy over the period 1978–80. Seizure descriptions were obtained, counselling provided, drug treatment reviewed and where appropriate altered and simplified with a move to monotherapy. An audit carried out in 1980 showed that polypharmacy was reduced in 24% of epileptic patients, seizure control appeared to be improved in 27% and improvement in general well-being was common and in a few patients dramatic.[7]

The active role taken by the practice in the care of patients with epilepsy or suspected epilepsy since 1978 is described in this paper and details of an audit carried out in 1986 are reported.

Method

The practice is situated in an urban area in Doncaster. There are four partners and the list size was 7500 in February 1986 at the time of the second audit; at the time of the first audit in March 1980 there were three partners and 6500 patients.

Patients with epilepsy were identified from a practice disease register and the information checked by a review of repeat prescribing of anticonvulsant drugs over a six-month period. The criteria for inclusion were active epilepsy, that is seizures in the previous two years, or seizures in the past and current treatment with anticonvulsant drugs. The diagnosis of a hospital specialist was the basis for the inclusion of most patients. Where evidence was strong and longstanding but no hospital evidence was available, the diagnosis was accepted. Patients who had had single seizures and febrile convulsions were excluded. Remission was regarded as two years without seizures while not taking anticonvulsant drugs.

Since 1978 the management of epilepsy in this practice has been based on the search for an accurate diagnosis and seizure classification (since the latter may determine choice of treatment), patient education, simplification of drug regimens including reduction of the number of drugs, and regular supervision. To enable valid comparison with other studies, the criteria for diagnosis in the 1986 audit used the new classification of seizures formulated by the International League Against Epilepsy.[13] These diagnostic criteria have also been applied retrospectively to the 1980 audit.

The withdrawal of anticonvulsant drugs depended on the drug combination, dosage, serum concentrations and side-effects and assumptions about which would be the most effective and least troublesome drug. No drug was discontinued until at least one major anticonvulsant drug was producing optimum serum levels. Withdrawal was always carried out slowly over several months. The drug was not always chosen by the general practitioner. When a drug was chosen by the doctor or when drugs had to be changed because of side-effects or failure to produce good control, the following order of preference was followed unless there was a special indication for one particular drug: carbamazepine, sodium valproate, phenytoin.

Results

Demography

The prevalence rates for patients with active epilepsy or receiving anticonvulsant drugs were 5.2 per 1000 patients in 1980 and 6.1 per 1000 patients in 1986. Figure 1 shows the changes among the epileptic patients between the audits of 1980 and 1986. Of the 37 patients described in the 1980 audit,[7] one has been ex-

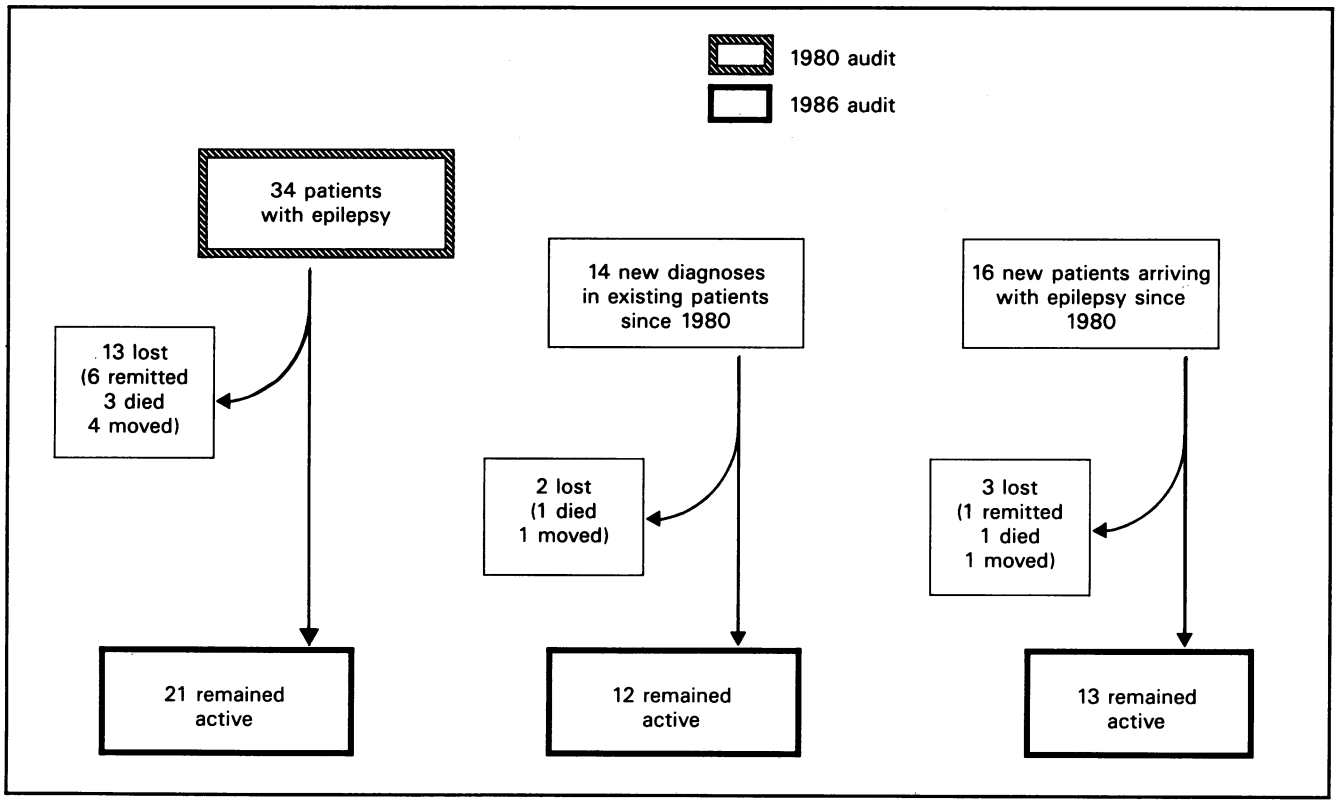

Figure 1. *Changes among epileptic patients in the practice over the period 1980–86.*

cluded as having febrile convulsions only, and two are now regarded as having been in remission. Including the latter two patients a total of 66 patients with epilepsy were studied over the period 1978–86. The median age of the seven patients remitting (Figure 1) was 29 years, and none of these patients had complex partial seizures or a tendency to many seizures.

Diagnosis and classification

Over the period 1980–86 problems of delayed diagnosis arose in one patient with complex partial seizures; and of mistaken hospital diagnoses in three patients, two of whom proved to have syncopal attacks, and the third suffered a single seizure only.

Table 1 shows the classification of seizure type for the 66 patients and lists separately those audited in 1980 and 1986. Of the 66 patients, six (9%) were subject to partial seizures only, with no secondary generalization. Those described as having generalized unspecified seizures were, in the absence of adequate descriptions, assumed to have tonic clonic seizures. On this assumption 60 (91%) of the patients were classified under tonic clonic seizures. Twenty-four patients (36%) had partial as well as secondary generalized seizures.

Possible aetiology of the epilepsy for 27 patients are shown in Table 2; six out of 22 patients over 40 years of age had underlying cerebrovascular disease as a possible cause of epilepsy.

Hospital involvement

It appeared from medical records that 41 out of the 46 patients in the 1986 audit had been seen at an early stage by a specialist, usually a neurologist or paediatrician. Electroencephalography had been carried out on these 41 patients — 23 were reported to be abnormal, five normal and the results for the remaining 13 were unknown. Computerized tomography had been carried out on 11 patients.

In the 12 months prior to the 1986 audit, 31 of the 46 patients were solely under general practitioner care, 10 had shared care provided by general practitioners and specialists and five were solely under specialist care (four of these were under paediatric care). Recent serum levels were recorded for 17 general practice patients.

Table 1. Classification of seizure type for the epileptic patients in the 1980 and 1986 audits and for all 66 epileptic patients (this includes some patients in neither audit).

	Number (%) of patients		
Seizure type	1980 audit ($n=34$)	1986 audit ($n=46$)	1978–86 ($n=66$)
Partial			
Simple partial	–	1	2
Complex partial	1	4	4
Complex partial evolving to secondary generalization	3	3	4
Total	4 (*12*)	8 (*18*)	10 (*15*)
Generalized			
Absence	–	–	–
Tonic clonic	8	11	20
Generalized (unspecified)	5	2	5
Total	13 (*38*)	13 (*28*)	25 (*38*)
Mixed seizure types			
Generalized absence and tonic clonic	5	5	7
Simple partial and secondary generalized	–	2	3
Complex partial and secondary generalized	12	18	21
Total	17 (*50*)	25 (*54*)	31 (*47*)

Table 2. Possible aetiology of epilepsy for 27 of the 66 patients.

Aetiology	Number of patients	
Post traumatic		
Head injury	2	
Subdural haematoma	1	
Cerebrovascular disease		
Diffuse	2	
Post-stroke	2	
Subarachnoid haemorrhage	3	
Vascular abnormality	1	
Central nervous system diseases		
Cerebral atrophy	1	
Gorlin's syndrome	1	
Tuberous sclerosis	2	(mother and daughter)
Meningioma	1	
Huntingdon's chorea	1	
Meningitis	1	
Cerebral abscess	1	
Others		
Mental subnormality	2	
Drug withdrawal	2	
Strong family history	4	(3 siblings and 1st cousin)

Seizure experience

Twenty-four of the 46 patients in the 1986 audit were free from tonic clonic seizures in the 12 months prior to the audit, but five of these patients continued to have partial seizures, which are harder to control. Therefore, 19 patients were totally seizure free. Seven patients reported less than three seizures per annum. Fifteen patients reported frequent seizures (more than three per annum); all these patients suffered complex partial seizures and all but one were subject to secondary generalization. Nine patients suffered more than one seizure each month.

For six patients with previously diagnosed epilepsy joining the practice after 1980, reduction of polypharmacy and adjustment of treatment led to improved seizure control for two patients — one had become seizure free for 12 months at the time of the 1986 audit. None of these six patients became worse, and five felt greatly improved mentally.

Drug treatment

Table 3 shows the number of drugs taken and the drugs used in the 1980 and 1986 audits and in a smaller audit carried out in 1981. It can be seen that the number of drugs taken by epileptic patients reduced over the period 1980–86. Of the 15 patients on two or more drugs in 1986, six had declined to reduce the number of drugs they were taking (and were seizure free), and a further five were taking clobazam as a second anticonvulsant drug in an attempt to reduce partial seizures. Five patients had chosen not to take anticonvulsant drugs. Two of these patients were free from fits and three were experiencing only occasional seizures.

Side-effects had been sufficiently troublesome to require changes in anticonvulsant therapy at some stage for 11 of the 46 patients in the 1986 audit.

Manipulation of anticonvulsant drugs within the practice led to few problems, with the notable exception in 1980 of one patient who developed encephalopathy with increased seizures after the phenytoin dosage was increased in response to low serum levels; sodium valproate, which competes for protein binding, was being taken concurrently. On the other hand, over the period 1980–86 four patients suffered exacerbations of seizures lasting several days following sudden changes in medication by hospital staff.

Discussion

The first audit in this practice, in 1980,[7] demonstrated improved seizure control and reduced number of drugs taken in a group of epileptic patients after two years of active management. The 1986 audit shows that the improvements have been maintained. Similar levels of seizure control have been achieved in the small number of patients with epilepsy who have joined the practice or who have been newly diagnosed. The rates of acquisition and apparent remission found in this small survey lend support to the concept of high life-time prevalence and the short-lasting nature of epilepsy for some.[4]

Over half of the epileptic patients in this study had few problems, and many of the remainder could be helped. Most of the difficulties and opportunities were with one-fifth of patients who suffered complex partial seizures. Many of these patients had poor control, were on multiple drugs or had suboptimal drug levels, and while some were attending hospital most were not. Many patients who benefited from intervention would not have done so had they not been sought out.

At the heart of the improvements in epileptic care in this practice has been a partnership between doctor, patients and relatives based on shared understanding of the individual's problems and shared decisions about any changes in treatment. This is a welcome and novel experience for many. Some patients prefer to continue treatment, even polypharmacy, rather than risk a recurrence of seizures and the adverse social consequences involved. Others prefer occasional seizures to taking tablets. Some find that avoiding tiredness, alcohol and boredom and being active and occupied reduces seizures.

A general practice initiative in managing epilepsy caused difficulties with hospital colleagues and occasionally there was a sense of competition for patient control rather than seizure control. Communication with hospital colleagues was also a problem.

The results reported here support the repeated calls for an improved epilepsy service. Neurologists, especially those with

Table 3. The number of anticonvulsant drugs taken per patient and the drugs used.

	Number (%) of patients		
	1980 audit ($n=34$)	1981 audit ($n=37$)	1986 audit ($n=46$)
Number of drugs taken per patient			
3	2	1	1
2	14 } (47)	13 } (38)	14 } (33)
1	16	23	26
0	2 } (53)	2 } (62)	5 } (67)
Drugs used			
Phenytoin	20	17	23
Carbamazepine	7	12	12
Phenobarbitone	10	9	3
Primidone	0	0	1
Sodium valproate	9	12	10
Clobazam	0	0	5
Sulthiame	1	1	1
Ethosuximide	2	1	0
None	2	0	5

a special interest in epilepsy, are few in number, and epilepsy care in the United Kingdom will continue to be shared between a variety of clinicians. The general practitioner enthusiast can meet many of the needs of his epileptic patients, but the small number of patients with epilepsy in the care of each general practitioner provide only a limited basis for expertise in complicated areas of management. General practice alone cannot make good the poor level of care currently provided for epilepsy sufferers.

The challenge is to exploit limited specialist expertise in collaboration with other clinicians and especially general practitioners. It is the author's view that local agreement should be reached on criteria and guidelines for managing epilepsy. A specialist service based on a local clinic should be the focal point, collaborative care could be assisted by the use of cooperation cards, and the creation of local epilepsy registers would enable long term surveillance and research.

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Is routine fetal monitoring really necessary?

The effect of using intrapartum electronic fetal monitoring in all pregnancies was compared with using it only in cases in which the fetus is judged to be at high risk. Predominant risk factors included oxytocin stimulation of labour, dysfunctional labour, abnormal fetal heart rate, or meconium-stained amniotic fluid. This prospective trial took place over a 36-month period during which 34 995 women gave birth.

Universal monitoring was associated with a small but significant increase in the incidence of delivery by ceasarean section because of fetal distress, but perinatal outcomes as assessed by intrapartum stillbirths, low Apgar scores, a need for assisted ventilation of the newborn, admission to the intensive care nursery, or neonatal seizures were not significantly different.

It was concluded that not all pregnancies, and particularly not those considered at low risk of perinatal complications, need continuous electronic fetal monitoring during labour.

Source: Levano KJ, Cunningham FG, Nelson S, *et al.* A prospective comparison of selective and universal electronic fetal monitoring in 34 995 pregnancies. *N Engl J Med* 1986; **315:** 615-619.